
Moving Forward: Transgender Persons as Change Agents in Health Care Access and Human Rights

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Transgender persons are on the front lines of negotiations on expectations of gender identity and expression. For the purpose of this report, transgender includes “any person who has a gender identity that is different from their natal sex and/or who expresses their gender in ways that contravene societal expectations of men and women” (Bockting, Robinson, Forberg, and Scheltema, 2005, p. 2).

Gender variations have strong roots in the histories of many cultures. Depictions of transgender persons have been found in artifacts from ancient Rome. Some North American indigenous cultures include two-spirit people, meaning that individuals who embody both genders have been part of native cultures. Various Hindu cultures embrace the concept of *hidras*, which is neither man nor woman (Lombardi, 2001). Samoans accept *fa’afafine* (also spelled *faafafine*, *fafafige*, or *fafafine*), biological males who choose or are chosen to be raised female and fulfill important domestic roles in Samoan culture. The Thai are tolerant of *kathoeys* (also spelled *katoey*), male-to-female (MTF) transgender persons who often work in traditionally feminine occupations (Croall & Elder, 1999; Matzner, 1999; Winter & Udomsak, 2002). Today, transgender may include “crossdressers, drag kings/queens, transsexuals, people who are androgynous, Two-Spirit people, and people who are bi-gendered or multi-gendered, as well as people who do not identify with any labels” (Bockting et al., 2005, p. 2).

Lack of acceptance of transgender persons in the United States is an important measurement of how far this country must go to realize its promise of equal

opportunity. Within the health care context, transgender individuals may experience invasive or inappropriate questions regarding sexual practices or genitalia, leading transgender persons to be suspicious of providers and health care institutions (O’Brien, 2003). Transgender persons who are in conflict with their sexual anatomy may be hesitant to discuss important issues regarding health care, including sexual practices or parts of the body that are biologically identified with sex or gender. It is not surprising that transgender persons are medically underserved or ostracized (Feldman & Goldberg, 2006).

If initiated correctly, workers in HIV/AIDS care who provide services to transgender persons can secure a trusting relationship in several ways such as querying about gender identity, concerns about treatment, and a person’s preferred name. For some transgender persons, the entry point to health care is seeking access to hormone therapy (Tom Waddell Health Center, 2001). In this case, the patient may enter care with a different priority than the provider, depending on the circumstances. Through greater understanding of a transgender patients’ concerns and health care goals, HIV providers can play a critically important role in helping the transgender patient achieve a higher quality of life.

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Background

Transgender is a term used for one's self-identification. It is not a disorder (Tom Waddell Health Center, 2001). Some transgender persons may choose to dress in the preferred gender clothing and/or change mannerisms and speech patterns. Other transgender people pursue medical treatment such as hormone therapy or sex reassignment surgery to complete gender identity transition (Human Rights Campaign and the National Center for Transgender Quality, 2007).

Transgender individuals who are experiencing gender dysphoria are given the diagnosis of gender identity disorder (GID). GID is a psychiatric classification. The classifications for GID listed in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* are 302.85 for adults and adolescents, 302.6 for children, and 302.6 for gender identity disorders not otherwise specified (i.e., disorders in gender identity that are not classifiable as a specific GID) (American Psychiatric Association, 2000). It should be noted that the *Diagnostic and Statistical Manual of Mental Disorders* and the World Health Organization's International Statistical Classification of Diseases and Related Health Problems, 10th Revision (World Health Organization, 2007) have 10 different subclassifications for GID for children not otherwise specified in adults. GID describes the confusion related to transsexuality, transgender identity, and transvestism. Often, this struggle produces feelings of despair, shame, guilt, and self-hate, leading to isolation, loneliness, hopelessness, depression, and even suicide (Bockting, Knudson, & Goldberg, 2006). The combination of any of these feelings can lead to validation seeking and high-risk behavior.

The diagnosis of GID and the term *gender dysphoria* have recently been met with resistance from the transgender community. The "disorder" label imposed on the individual is certainly controversial. Diagnosing a transgender patient with dysphoria brands the individual with a mental pathology instead of recognizing the patient's location outside a binary gender construct defined as normal by society (Bockting et al., 2006). More alarming is the subjugation of children who do not conform to dominant gender norms to psychotherapy, behavior modification, and institutionalization

(Planned Parenthood of the Southern Finger Lakes, 2006).

Transgender Terminology

Transgender persons as patients are a diverse group with a wide range of terms for self-identification (see Table 1). These terms can be used interchangeably by the transgender community. The use of these terms can cause confusion on the part of the provider who may unknowingly offend the patient. Additionally, some terms are used by members of the community, whereas others may find them offensive. Certain terms are "yellow flag language" and should be avoided (see Table 2). Also, the use of pronouns by the provider may not be in agreement with the patient's gender identity. The easiest way to prevent unease is to ask the patient to specify gender. It is respectful for the provider to use the transgender patient's chosen name, and it is never appropriate to place the chosen name or gender identity in quotations (Gay & Lesbian Alliance Against Defamation, 2008). The array of interchangeable terminology reflects the many ways that individuals experience and express gender, including biologically, psychologically, socially, and culturally (Lombardi, 2001).

Epidemiology

Transgender people are not included in the U.S. Census. Estimates of the numbers of transgender people are somewhat controversial because the data do not include people who have not yet undergone or choose not to have sex reassignment surgery (Olslager & Conway, 2007).

When considering HIV risk for transgender persons, it is critical to remember that simply being a transgender person does not place a person at risk. Instead, health care providers should not only consider sexual risks common to all groups but also life circumstances such as mental health concerns, physical abuse, social isolation, and economic marginalization (Herbst et al., 2008). People who have experienced victimization may place the blame on themselves (Ryan & Rivers, 2003).

Table 1. Transgender Terminology**Sex**

The classification of people as male or female. At birth, infants are assigned a sex based on a combination of bodily characteristics including hormones, internal reproductive organs, and genitals.

Gender identity

One's internal, personal sense of being a man or a woman (or a boy or girl). For transgender people, their birth-assigned sex and their own internal sense of gender identity do not match exactly.

Gender expression

External manifestation of one's gender identity, usually expressed through masculine or feminine behavior, clothing, haircut, voice or body characteristics. Typically, transgender people seek to make their gender expression match their gender identity rather than their birth-assigned sex.

Sexual orientation

Describes a person's physical, emotional and/or spiritual attraction to another person. Gender identity and sexual orientation are not the same. Transgender people may be heterosexual, lesbian, gay, or bisexual. For example a male who becomes a woman and is attracted to men would be identified as a heterosexual woman.

Transgender

An umbrella term for people whose gender identity and/or gender expression differs from the sex they were assigned at birth.

Transgender may include but is not limited to: transsexuals, intersex people, cross-dressers, genderqueer and other gender-variant people. Use the descriptive term (transgender, transsexual, cross-dresser, female-to-male, male-to-female, genderqueer, etc.) preferred by the transgender person. Transgender people may or may not choose to alter their body hormonally and/or surgically.

Transsexual

An older term that originated in the medical and psychological communities. Just as many gay people prefer *gay* to the medical term *homosexual*, many transgender people prefer *transgender* to *transsexual*. However, some transsexual people still prefer to use the medical term to describe themselves. It is best to ask someone which term they prefer.

Transition

Altering one's birth sex is not a one-step procedure—it is a complex process that takes place over a long period of time. Transition includes some or all of the following cultural, legal, and medical adjustments: telling one's family, friends, and/or co-workers; changing one's name and/or sex on legal documents; hormone therapy; and/or possibly (though not always) some form of chest and/or genital alteration. Preferred over the term *sex change operation*.

Sex reassignment surgery

Refers to genital alteration, and is only one small part of transition (see *transition*). Not all transgender people choose or can afford to have sex reassignment surgery. Preferred to the term *sex change operation*.

Cross-dressing

To occasionally wear clothes traditionally associated with people of the other sex. Cross-dressers are usually comfortable with the sex they were assigned at birth and do not wish to change it. (*Cross-dresser* should not be used to describe someone who has transitioned to life full-time as the other sex or who intends to do so in the future.) Cross-dressing is a form of gender expression. It is not necessarily tied to sexual orientation or erotic activity. Most cross-dressers are heterosexual men. Very few women identify as cross-dressers.

Gender identity disorder

A controversial medical/psychiatric diagnosis given to transgender and other gender-variant people. Because it labels people as disordered, gender identity disorder is often considered offensive. The diagnosis is frequently given to children who do not conform to expected gender norms in terms of dress, play, or behavior. Such children are often subjected to intense psychotherapy, behavior modification, and/or institutionalization. Replaces the outdated term *gender dysphoria*.

Intersex

Describing a person whose biological sex is ambiguous. There are many genetic, hormonal or anatomical variations that make a person's sex ambiguous (e.g., Klinefelter syndrome, adrenal hyperplasia). Parents and medical professionals usually assign intersex infants a sex and perform surgical operations to conform the infant's body to that assignment. This practice has become increasingly controversial as intersex adults are speaking out against the practice, accusing doctors of genital mutilation. Replaces the outdated term *hermaphrodite*.

SOURCE: Planned Parenthood of the Southern Finger Lakes (2006), pp. 16-18.

The Centers for Disease Control and Prevention does not collect data on the incidence or prevalence of HIV in the transgender community. Data that exist have been collected by regional jurisdictions that

provide services to the transgender community. The most current estimates of HIV prevalence among the transgender community were published in a systematic review of HIV behavioral literature

Table 2. Yellow-Flag Terms and Terms to Avoid**Yellow-Flag Terms^a****Genderqueer**

A term often used by people whose gender identity is fluid and does not neatly fit into “man” or “woman,” or by people who reject our society’s binary gender system. People who identify as genderqueer typically do not identify as a man or a woman because neither gender accurately describes them (p. 18).

Queer

Blurs both gender and sexual orientation and is regarded by some as more inclusive than the terms *gay* or *lesbian* because it encompasses both sexual orientation and gender identity. Some people also regard the word *queer* as offensive and derogatory because of its history of being used as a slur (p. 18).

Tranny; trannie

Slang; some transgender people choose to refer to themselves as a tranny or trannie. Some transgender people find these terms offensive and dehumanizing. Your best bet is to refer to people as they refer to themselves, or use the widely accepted term *transgender* unless someone asks you to use another term (p. 18).

Terms to Avoid

Problematic: *transgendered*

Preferred: *transgender*

The word *transgender* never needs the extraneous -ed.

Problematic: *sex change, preoperative, postoperative*

Preferred: *transition*

Referring to a sex change operation or using terms such as *preoperative* or *postoperative* inaccurately suggests that one must have surgery to truly change one’s sex. The term *transition* is more universal and encompasses many other steps that transgender people may take to change their sex.

Problematic: *hermaphrodite*

Preferred: *intersex person*

The word *hermaphrodite* is a stigmatizing and misleading word, usually used to sensationalize intersex people. *Intersex* is a more accurate and less incendiary term.

Defamatory: *deceptive, fooling, pretending, posing, masquerading*

Gender identity is an integral part of a person’s identity. Please do not characterize transgender people in this way; such descriptions are extremely insulting.

Defamatory: *she-male, he-she*

These words only serve to dehumanize transgender people and should not be used.

SOURCE: Planned Parenthood of the Southern Finger Lakes (2006), pp. 18-19.

a. These “yellow-flag” terms are accepted by some and regarded as offensive by others.

from the United States (Herbst et al., 2008). HIV infection estimates for MTF transgender persons ranged from 11% to 28% (i.e., 11.8% MTF’s self-reported that they tested positive, whereas 27.7% MTFs tested positive). African American MTFs had higher rates of HIV infection by both assessment methods (i.e., self-report and testing) than White or Latino MTFs. Additionally, MTF trans youth of color may be disproportionately impacted by the AIDS epidemic in the United States (Sausa, 2003). Trans youth report higher rates of victimization in comparison with lesbian, gay, or bisexual youth, which places them at risk for HIV infection (Ryan & Rivers, 2003).

There exists even less information on female to male (FTM) transgender persons. Herbst et al. (2008) reported low prevalence rates of HIV infection

and risk behavior in this group. Despite low prevalence rates, FTMs were reported to be engaging in high risk behavior. Compared with MTFs, FTMs were less likely to have used protection the last time they had sex and much more likely to have engaged in recent high-risk sexual activity (Kenagy & Hsieh, 2005). This risk is further increased in FTMs who are attracted to males because they report oral, anal, and vaginal intercourse (Bockting et al., 2005) with condom use reported as sporadic (Clements-Nolle, Marx, Guzman, & Katz, 2001).

Clinical Environment Issues

Patients need to have a sense of trust in and respect from their providers (see Table 3). The first step in

Table 3. Clinic Environment Considerations Used at the University of Nebraska Medical Center HIV Clinic to Provide Transgender-Inclusive Care

<i>Preferred name vs. legal name.</i> Private insurance and governmental assistance programs may require the transgender patient's legal name and not chosen name for billing purposes. Providers should include an option for chosen name and use this name when interacting or discussing the patient.
<i>Use of pronouns.</i> If there is doubt regarding the transgender patient's choice of pronoun, politely ask the transgender patient the pronoun of gender identity. This pronoun should be used by all of the staff when speaking to or about the patient.
<i>Inclusive environment.</i> Availability of unisex bathrooms and gender-neutral forms or forms with options indicate a welcoming atmosphere to transgender patients.
<i>Hormone therapy.</i> The interaction between hormones used for transgender therapy and HIV medications has not been studied. For some HIV-infected transgender patients, seeking access to hormones is an incentive to seek HIV care. With few exceptions, hormones and anti-HIV therapy are not contraindicated; however, the provider must consider potential adverse effects of hormones such as high blood pressure, cardiovascular disease, cholesterol increase, and liver disease.
<i>Mental health.</i> Although not all transgender patients will need a referral for mental health services, it is important to consider the stigma that society places on the transgender patient and its negative impact. Referral to mental health providers who are sensitive to transgender concerns should be made as indicated.

establishing these bonds with a transgender patient is the use of name and pronoun congruent with the person's gender identity. In addition to routine HIV care, the provider will need to assess the transgender patient's specific concerns such as hormones use, surgery, or other enhancements. The provider should explore psychosocial needs such as thoughts on transitioning, housing, social support, violence, and employment. However, the provider will have more success in approaching these complex issues after securing trust during the initial visit. If a transgender patient is self-administering hormones, the provider should initiate a conversation regarding potential consequences of street hormone use and needle sharing. Having HIV infection is not contraindicated with hormone therapy; however, the interactions between hormones and anti-HIV medication may pose complications and risks. No evidence-based interventions exist for guidance at this time, and further research in this area is warranted. It is important to be mindful of the potential for adverse effects such as cardiovascular disease, hyperlipidemia, and thrombosis. Despite the associated risks with hormone therapy, some transgender patients will chose the benefit of a physical body in accord with their gender identity over health and safety.

Human Rights Issues

Normalization of gender and sexual orientation can come in the form of social customs and/or direct

enforcement by means of the law, coercion, or violence ([The Yogyakarta Principles, 2006](#), p. 6). In the United States, only 12 states and the District of Columbia ban discrimination against gays and lesbians and ban discrimination based on gender identity. Eight states ban discrimination based on sexual orientation only, without mention of gender identity ([Human Rights Campaign, 2008](#)). Roughly 70% of the country's population live in states without such antidiscrimination laws

Within the health care context, the recent provider conscience regulation issued by the last Bush Administration has caused concern within the transgender community. Through this regulation, the Bush Administration sought to ensure that conscience clauses (i.e., refusal clauses) were observed by entities that receive funds from the U.S. Department of Health and Human Services ([U.S. Department of Health and Human Services, 2008](#)). Congress initiated the first conscience clauses through the Church Amendment following the Supreme Court's 1973 *Roe v. Wade* decision. The Church Amendment allowed health care providers to cite religious grounds in refusing to administer abortions.

In the last 35 years, conscience clauses have expanded to include "reproductive technologies, contraception or emergency contraception, human embryonic or fetal research, in vitro fertilization, and stem cell research" ([Planned Parenthood Federation of America, 2004](#)). Problematically, the new provider conscience rule not only could block access to contraceptives and abortions but also gay, lesbian,

and transgender persons' access to medical services at entities and clinics receiving funds from the Department of Health and Human Services. Hypothetically, some providers may choose to use the rule to deny services to individuals whose lifestyle is in opposition to their "moral, religious, or even personal beliefs" (National Center for Transgender Equality, 2009). In late February, the Obama administration announced the intent to overturn this controversial rule (Rovner, 2009).

With this in mind, what role can health care workers in HIV/AIDS care perform in the promotion of health care access and human rights for transgender persons? The Yogyakarta Principles, a set of applications of international human rights law in relation to sexual orientation and gender identity, offer health care workers a template for answering this question. Principle 17 indicates: "Everyone has the right to the highest attainable standard of physical and mental health, without discrimination on the basis of sexual orientation or gender identity...." (p. 22). Moreover, Principle 17 directs nation-states to

Ensure that health care facilities, goods and services are designed to improve the health status of, and respond to the needs of, all persons without discrimination on the basis of, and taking into account, sexual orientation and gender identity...[and to] ensure that all persons are informed and empowered to make their own decisions regarding medical treatment and care" (Yogyakarta Principles, 2006, p. 22).

Achieving access to health care for all transgender persons undoubtedly requires greater sociopolitical acceptance of individual expression of identity, regardless of birth gender or social role expectations. In their pursuit of the right to health care, transgender persons may choose a civil rights or minority rights discourse. No matter the route, transgender persons are change agents moving our society and country toward greater institutional and social acceptance of health care as a human rights issue. Health care workers in HIV/AIDS care can seize this opportunity to partner with transgender persons on the increasingly important and timely discussion of health care as a human right.

Conclusion

Transgender patients may encounter less than optimal or negative health care, which heightens the burden of HIV transmission and morbidity within this community. Transgender people also confront legal factors, social norms, and perhaps the ethics of HIV providers. In light of these issues and the basic sociocultural misunderstanding that transgender persons experience from an early age, it is time to move the interests of transgender patients forward.

In making care more inclusive, providers should not dismiss small steps such as unisex bathrooms and asking the transgender person for preferred name/gender identity. Although subtle, these measures are overt acknowledgments of a transgender patient's inclusion. For a transgender person, transitioning is a life process. This process will take place with or without sensitive care and services from health care providers. However, providers in AIDS care can advance stronger systems of care for all HIV-infected individuals by partnering with transgender persons to enhance understanding and acceptance.

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